

My name is Therese Waters and I am writing this letter to support telemedicine in Northern Michigan. I am the parent of Kelly Waters, a 22 year old with homocystinuria (HCU), a rare genetic disorder- one of the inborn errors of metabolism. Although Kelly was born with her disorder, she was not diagnosed until the age of 6. Children with HCU cannot metabolize one of the amino acids in protein and without a protein-free diet and special medical formula, they suffer from mental retardation, visual loss, growth and neurological issues as well as formation of blood clots- frequently resulting in strokes or death. We lived in Lansing during Kelly's childhood and Kelly had many specialists due to the scope of her symptoms and rare nature of her disorder- in Grand Rapids, Lansing and Detroit. We moved to Traverse City 4 years ago.

Kelly was able to continue to see her U of Michigan doctor here because of their Munson satellite clinic. She has some new adult specialists locally. She does, however, need to see a hematologist/oncologist but none of the local adult specialists here is willing to see her. Recently, we found that her specialists from MSU are now seeing patients in Traverse City through Munson's telemedicine clinic. This is wonderful for us as Kelly cannot drive due to her visual impairment and constant out of town travel is disruptive to my work schedule and her school schedule. Clinic visits can take at least a day and usually overnight. We are also concerned that in the event of a local hospitalization, her out of town specialists will have no relationships with the local physicians. The telemedicine clinic solves these issues.

Additionally, I have become an active parent advocate for children with genetic and rare disorders. I have been involved with the Newborn Screening Advisory Committee since 2004 as well as the Region IV Genetic Collaborative funded thru HRSA and attended the NICHQ conference and Genetic Diseases of Children conferences to gain further insight and collaborate with other parents and professionals on improving access, equity and quality of care. As a parent and physical therapist, I have encountered many other parents, clinicians and other providers who share my concerns.

Northern Michigan is a wonderful place to live and work. The quality of medical care is top notch but the established specialty clinics are typically downstate. Children with rare disorders and conditions are forced to travel to one or more large downstate providers for their care. Many families cannot afford the time away from work or the travel expense to make multiple clinic visits. Parents know that if their child is suddenly hospitalized, there is only a distant relationship between their clinic specialists and the local doctor.

A few years ago, CSHCS stopped reimbursing families for mileage to clinic visits. The mileage reimbursement did not even begin to cover the costs of a clinic visit 2-5 hours away, but it did help. I was made aware of a child who was taken off a transplant eligibility list due to his family's inability to keep his clinic appointments. Other families frequently cancel and skip clinic visits because they cannot afford to travel or to take time off of work. This problem is magnified with the distance to downstate specialty clinics and puts children's health in jeopardy.

The genetic metabolic clinic for the state is in Detroit with limited satellites in Southfield and Grand Rapids. I have been advocating for telemedicine visits *all* over the state to give these children equal access to care, especially in Northern Michigan. I support any efforts to make this service a reality for the children here and their families to provide the equity, access and quality of care they deserve.

Respectfully,

Therese Waters, PT

Mother of Kelly, age 22 (non B-6, non B-12 responsive homocystinuria)

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